The Texas Birth Defects

MONITOR

An Annual Data and Research Update

TEXAS Health and Human Services | Texas Department of State Health Services

Volume 25 **December 2019**

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Family Outreach Activities of the Texas Birth Defects Epidemiology and Surveillance Branch—Neural Tube Defect Recurrence Prevention Initiative

In 2017, the Texas Birth Defects Epidemiology and Surveillance (BDES) Branch relaunched its Neural Tube Defect (NTD) Recurrence Prevention Project as a part of the Centers for Disease Control and Prevention (CDC) cooperative agreement, "Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization". The purpose of this grant-funded initiative is to reduce the risk of another NTD-affected pregnancy (anencephaly, spina bifida, or encephalocele) in women who have had a recent affected pregnancy. BDES mails information to these women, describing their increased risk for NTDs in future pregnancies and providing information about high dose folic acid supplements to reduce the risk of a recurrence. Research has shown that high-dose folic acid supplements (4 mg per day) used by women who had a prior NTD-affected pregnancy reduces the risk of having a subsequent NTD-affected pregnancy by 70%. The packet also provides information in English and Spanish about additional resources available to families, such as the Texas Teratogen Information Service and the 2-1-1 Texas hotline.

The Branch evaluated the effectiveness of the NTD recurrence prevention mailing by surveying selected women who received the mailing. Public Policy Research Institute (PPRI) at Texas A&M University conducted the survey on behalf of BDES.

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Sign up for email updates from the Texas Birth Defects Epidemiology and Surveillance Branch at dshs.texas.gov/birthdefects/.

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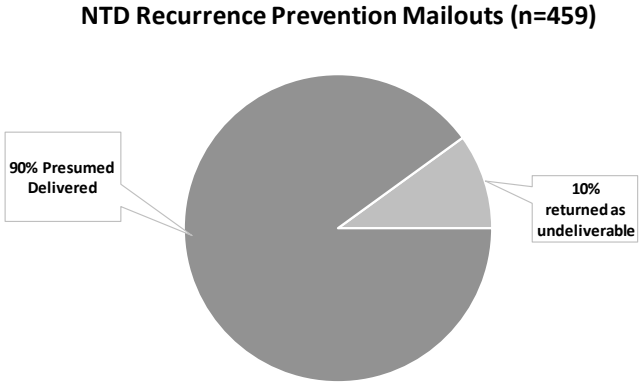
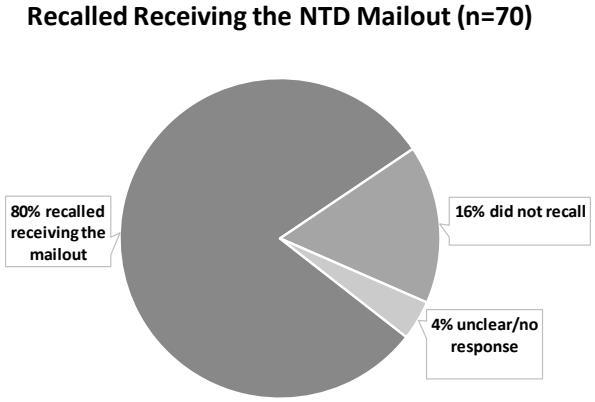
The purpose of the survey was to determine whether women recalled receiving the mail-outs and if they understood the recommendations regarding folic acid.

- Of the 459 letters sent, 90% (412/459) were presumed delivered (they were not returned to us as undeliverable)
- 71 of 177 mothers selected for the survey (40%) completed the survey, either by phone or internet
- Of 70 biological mothers who completed the survey, 80% (56/70) recalled receiving the NTD recurrence prevention mailing
- Of the 56 mothers that recalled receiving the mailing, 57% (32/56) demonstrated accurate knowledge about folic acid for prevention of NTDs
- 59% of mothers (41/70) indicated that they had not previously received information from another source about the vitamin folic acid and how it lowers the risk of NTDs.

Results from the surveys showed that mailing NTD recurrence prevention information to affected women is a useful initiative. BDES will continue the mail out initiative and regularly reevaluate the information packet.





These family outreach activities were supported in part by the Centers for Disease Control and Prevention (CDC) grant CDC-RFA-DD16-1601, "Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization," and Title V, Children with Special Health Care Needs, and Texas Parent-to-Parent Family Support Group.

Case Management Partnership with DSHS Regional Specialized Health and Social Services

As part of a cooperative agreement between the Texas Department of State Health Services (DSHS) and Centers for Disease Control and Prevention (CDC) entitled "Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization," the Birth Defects Epidemiology and Surveillance Branch implemented a referral/case management program in 2016. The goal of this program is to connect families of children with birth defects to services and identify barriers to receiving services. The program targets children ranging from 6 to 24 months of age, who are born with certain birth defects, as identified by the Texas Birth Defects Registry (currently spina bifida, encephalocele, orofacial clefts, and Down syndrome). In order to reduce the likelihood that families of deceased children are contacted, the Branch conducts a linkage with death records prior to referral.

The Texas Birth Defects Registry (TBDR) shares cases with the DSHS Specialized Health and Social Services (SHSS) licensed social workers in regional offices, located near where the case families live. Social workers make attempts to contact families by mail, phone, or home visit. If a family decides to engage in case management, social workers then assist the family. Social workers also use an evaluation form developed to collect information on the needs of each family.

Of the 626 selected live-born cases referred from the TBDR to DSHS regional social workers, 6 (1%) families were not contacted as their child was identified as deceased by a social worker. Successful contact was made with 419 (67.6%) of the remaining 620 parents/guardians, all of whom resided in Texas at the time of delivery.

- Out of the 419 family contacts, 345 of the young children (82.3%) were on some form of Medicaid alone (not dually enrolled in another form of insurance)
- 210 (50.1%) were enrolled in Early Childhood Intervention (ECI) services
- Most children (98.8%) were receiving services from a pediatrician
- Roughly 55% of all children were not meeting developmental milestones
- Over 90% of families were unaware of Texas Parent to Parent, a statewide family support organization
- Licensed social workers were able to refer families to various healthcare services or organizations based on family interest and their needs to assist children in optimal care
- A total of 91 (43.5%) of the remaining 209 children not already enrolled into Early Childhood Intervention (ECI) services were newly referred
- 151 (36%) children were referred to Medicaid Waiver programs
- Additionally, 306 (73%) of families were newly referred to Texas Parent to Parent

The case management program helps connect Texas families to important social service programs in their area and allows BDES to gain a better

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These family outreach activities were supported in part by the Centers for Disease Control and Prevention (CDC) grant CDC-RFA-DD16-1601, "Birth Defects Surveillance in Texas: Methodological Enhancement and Impactful Data Utilization," and Title V, Children with Special Health Care Needs, and Texas Parent-to-Parent Family Support Group.

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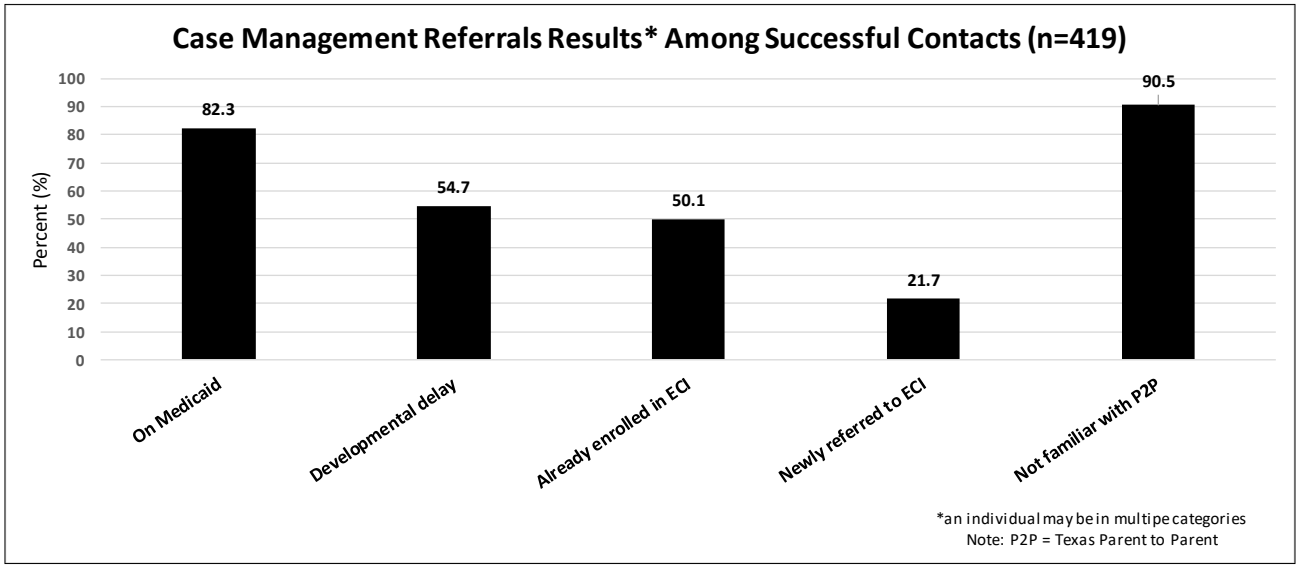
understanding of some of the challenges and barriers that families face. BDES plans to continue the referral program and will continue to evaluate the initiative and make changes as needed to best meet the needs of affected children.



Children with Special Health Care Needs: A Resource Guide for Families is available on the website in English and Spanish. Visit dshs.texas.gov/birthdefects/ access the brochure and learn more about services and organizations available to children with special health care needs.

world birth defects day
march 3

The International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR) and participating organizations are raising awareness of birth defects with World Birth Defects Day, held on March 3. The ICBDSR hopes to increase global awareness of birth defects and promote expansion of birth defects surveillance, prevention, research, and care with this event.

To learn more, visit icbdsr.org/.

Updated Data from the Texas Birth Defects Registry

Updated data from the Registry is now available on the BDES website in the Texas Birth Defects Registry Report of Birth Defects Among 1999-2016 Deliveries.

In addition, data visualizations from the Report are also available on the Texas Health Data website. These visualizations include Prevalence of Selected Birth Defects among Deliveries to Texas Residents by:

- Year
- Sex of Infant or Fetus
- Maternal Race/Ethnicity
- Mother's Age
- Pregnancy Outcome

Access the Texas Birth Defects Registry Report of Birth Defects Among 1999-2016 Deliveries and the data visualizations from the report at dshs.texas.gov/birthdefects/Data/reports.shtm.

Save the Date

National Birth Defects Prevention Network 23rd Annual Meeting

The National Birth Defects Prevention Network (NBDPN) Annual Meeting will be held in Arlington, Virginia at the Renaissance Arlington Capital View Hotel on March 9-11, 2020. This year's topics will include sessions on national standards and analytical methods for birth defects surveillance, prevention strategies, disorders of the head and brain, and many other important topics in the field of birth defects surveillance and research.

The NBDPN Annual Meeting is the only national conference for population-based birth defects surveillance systems in the United States. Participants are able to learn about various topics in surveillance, research, intervention, and prevention. To learn more about the 2020 NBDPN Annual Meeting, and for topic and registration details, visit nbdpn.org/2020am.php.

2020 Biennial Technical Training

The 2020 Biennial Technical Training for BDES staff will be held November 17-19, 2020 in Austin, Texas. The training will focus on a variety of topics, with a special focus on data quality and training for regional staff.

The Association between Newborn Screening Analytes and Childhood Autism in a Texas Medicaid Population, 2010–2012

Autism, or Autism Spectrum Disorder (ASD), is a developmental disorder of varying severity that is usually diagnosed around age three. The cause of the condition is unknown; however, research has shown a genetic cause in some individuals with the condition. In addition, recent research has focused on ASD biomarkers due to high heritability of the condition between siblings. To date, there are no established postnatal biomarkers for ASD. The authors of this study explored whether newborn screening results may provide some clues by examining the association of newborn screening analytes with an ASD diagnosis in a Texas Medicaid population.

At birth, all Texas newborns are screened for rare, serious disorders through blood spot tests. The first screening takes place soon after delivery, and the second takes place at least one week later. The goal of newborn screening is to detect markers for these disorders, known as analytes. The Department of State Health Services laboratory then receives the blood samples for testing. Finding and treating these disorders early can prevent serious complications such as growth and developmental delays, deafness, blindness, intellectual disabilities, seizures, and early death.

In this case-control study, researchers looked at three to five-year-old children who received Medicaid services from 2010 to 2012. Cases included children with any Medicaid diagnosis of ASD, and controls were children without ASD matched 2:1 to cases on sex, and birth month and year. The Medicaid records were linked to 2007-2009 birth certificates and newborn screening lab records (for analyte values). The analyte values were grouped into ten levels (called deciles); for example, the lowest 10% of values were in decile 1, the next 10% of values in decile 2, etc. Next, the team examined the association of a range of factors from the birth certificate (i.e., covariates) with a later ASD diagnosis. Finally, they examined the association of 36 newborn screening analytes with ASD, after adjusting for significant covariates.

Nine of these covariates were significantly associated with ASD: paternal and maternal age, maternal race/ethnicity, residence (urban/rural), parity, body mass index, birthweight, C-section, and use of antibiotics in labor. The strongest associations of covariates with ASD were:

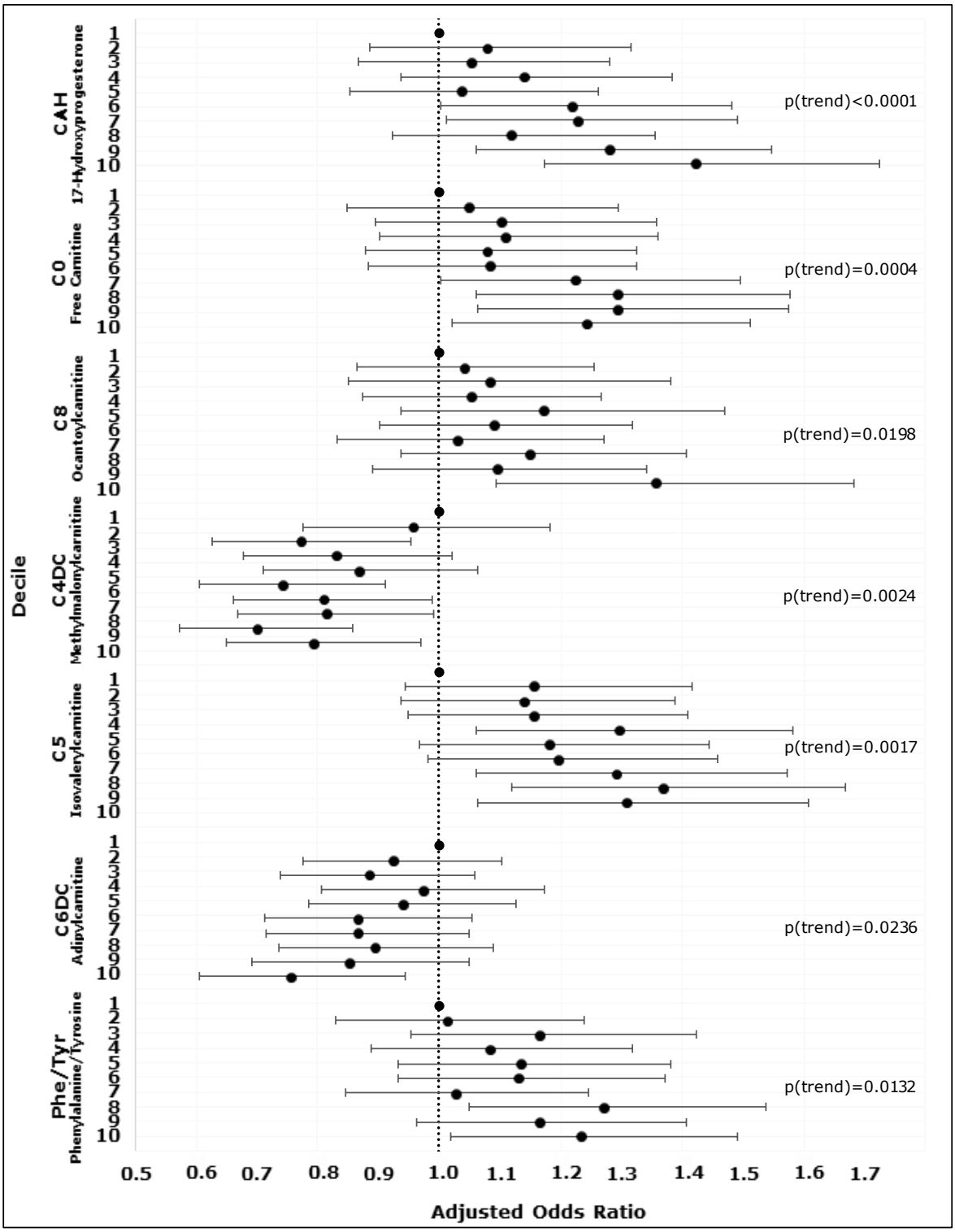
- low birthweight (41% higher risk)
- teen father (32% lower risk)
- rural residence (31% lower risk)
- Non-Hispanic black mother (30% lower risk)
- Non-Hispanic Asian/American Indian mother (41% lower risk)

After adjusting for the nine covariates listed above, the authors analyzed 36 analytes and ASD (see figure on page 5).

- 19% of all analytes (7 of 36) were associated with a later autism diagnosis (i.e., significant result for 10th vs. 1st decile and for trend)
- 1 hormonal analyte (17-hydroxyprogesterone): 42% increased risk in the 10th decile vs. 1st)
- 3 acylcarnitines and 1 amino acid ratio – positive associations (23-36% increased risk)
- 2 acylcarnitines – negative associations (21-24% decreased risk)
- No association found with thyroxine, methionine, or other analytes

This was an exploratory study to assess the association between a full range of analytes from newborn screening and later diagnosis of ASD in a large study population. ASD is associated with a constellation of defects that cause developmental problems. While ASD is not a birth defect, as in a structural malformation, it is a condition that may be present in early infancy that doesn't manifest until developmental delays are noticed.

Adjusted Odds Ratios* for the Association of Autism Spectrum Disorder with Selected Newborn Screening Analytes, Texas



*Adjusted odds ratios: adjusted for maternal race/ethnicity, maternal age, paternal age, rurality of residence, parity, body mass index, birthweight, antibiotics during labor, and Cesarean delivery

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Folic Acid Awareness Week is January 5-11, 2020

January 5-11 is Folic Acid Awareness Week, but folic acid should be part of a healthy lifestyle every day.

What is folic acid and why do you need it?

- Folic acid is an essential B-vitamin; therefore, everyone needs it in order to stay in good health. Folic acid helps build DNA and your body uses it for cell growth and reproduction, fundamental building block processing and genetic material production.
- In 1998, the U.S. Food and Drug Administration started fortifying cereal grain products with folic acid in order to reduce the risk for neural tube defects (NTDs), serious birth defects of the brain and spine. While this was a great step in the fight to prevent birth defects, it is often not enough to protect all women and their potential children.
- Folic acid is water soluble, therefore it passes through your body very quickly. Taking folic acid every day ensures that you always have it in your system when your body needs it.
- It is particularly important for women of reproductive age to get 400 mcg of folic acid daily. It has been shown to reduce the risk of having an NTD by up to 70%. Since about 50% of pregnancies in the United States are unplanned, it's important to take folic acid every day, even if you're not planning to get pregnant. The most common NTDs are spina bifida and anencephaly.

Who needs folic acid?

All women need folic acid every day. Getting enough folic acid every day, before and during early pregnancy, is an important way to reduce the risk of NTDs. These birth defects occur in the first weeks of fetal development, often before a woman even knows she is pregnant.

Some women may be at higher risk. Not only do Latinas have higher rates of NTD-affected pregnancies, but they also have the lowest awareness/knowledge about folic acid than non-Hispanic women. In addition, Latinas consume less folic acid than non-Hispanic women.

January is National Birth Defects Prevention Month

January is National Birth Defects Prevention Month. Not all birth defects can be prevented. However, women are encouraged to make healthy choices and adopt healthy habits to help lower their risk of having a baby born with a birth defect. In addition to regularly taking the recommended amount of folic acid, planning ahead, avoiding harmful substances such as alcohol and smoking, and choosing a healthy lifestyle by eating a healthy diet and exercising, are also important for a healthy pregnancy.

Women who plan to become pregnant should visit their healthcare provider to get a medical checkup, and discuss their medications and family medical history.

The National Birth Defects Prevention Network is working together with many state and local organizations to raise awareness of birth defects and how to prevent them. Learn more about the effect you can have on birth defects awareness and prevention at nbdpn.org/bdpm.php.

(Recent Publications from BDES Branch Staff and Collaborators Continued from Page 8)

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The Monitor is published annually by the Birth Defects Epidemiology and Surveillance Branch, Texas Department of State Health Services.

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Please visit the BDES website for updated information and to sign up for Branch updates: dshs.texas.gov/birthdefects/.

Requests for copies or back issues may be made to: birthdefects@dshs.texas.gov.

2020 Calendar

- January: National Birth Defects Prevention Month
- January 5-11: National Folic Acid Awareness Week
- February: American Heart Month
- February: International Prenatal Infection Prevention Month
- February 14: Congenital Heart Defect Awareness Day
- Spring 2019: March of Dimes March for Babies (check with MOD for specific dates and locations)
- March: National Nutrition Month
- March: National Developmental Disabilities Awareness Month
- March 21-24: Association of Maternal and Child Health Programs (AMCHP) Annual Conference, Crystal City, Virginia
- March 8-11: National Family Planning & Reproductive Health 2019 National Conference, Washington D.C.
- April: Alcohol Awareness Month
- April: National Autism Awareness Month
- April: National Minority Health Month
- April 6-12: National Public Health Week
- June 15-16: 33nd Annual Meeting of the Society for Pediatric and Perinatal Epidemiologic Research, Boston, MA
- June 27-July 1: 60th Annual Meeting of the Teratology Society, Charleston, South Carolina
- July: National Cleft and Craniofacial Awareness & Prevention Month
- July 30: Gastroschisis Awareness Day
- September: Newborn Screening Awareness Month
- September: National Infant Mortality Awareness Month
- October: National Spina Bifida Awareness Month
- October: National Down Syndrome Awareness Month
- October 5-7: 47th International Clearinghouse for Birth Defects Surveillance and Research Annual Meeting, Bologna, Italy
- October 24-28: American Public Health Association Annual Meeting, San Francisco, California
- November: Prematurity Awareness Month (March of Dimes)

This publication was supported in part by the Office of Title V & Family Health, Texas Department of State Health Services, using Title V Maternal and Child Health Block Grant Funds.

DSHS Pub. No. 58-10955